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Department of
Obstetrics & Gynecology

Clinician Perspectives on the Need for Training on Caring for Pregnant Women with Intellectual Disabilities

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INTRODUCTION

- Rates of pregnancy among women with disabilities are increasing¹.
- Women with intellectual and developmental disabilities (IDD) are more likely to experience preterm deliveries, low birth weight infants, and stillbirths^{2,3}.
- Women with IDD also have elevated rates of postpartum emergency department visits and hospitalizations^{4,5}.
- One important barrier to receipt of adequate and appropriate health care for people with IDD is the lack of appropriate training for healthcare professionals^{6,7}.

AIM

- The objective of this study was to examine clinician perspectives on training and training needs regarding the care of pregnant women with IDD.

METHOD

- We conducted individual interviews (n=9) and one focus group (n=8) with obstetric clinicians about their experiences providing obstetric care to women with IDD.
- Using a content analysis approach, the study investigators reviewed and discussed several transcripts to identify concepts emerging from the data using both inductive and deductive techniques.
- The concepts were converted to codes documented in a codebook which were then expanded and collapsed before being grouped in categories or themes.

RESULTS

Our analysis revealed **three main themes**:

1) Need for education and training including the clinician participants' own limited training experiences as a barrier to care for pregnant women with IDD.

- No participant reported receiving any training in caring for pregnant women with IDD
- Participants expressed a need for formal education

2) Recommendations for how to disseminate formal training and to what groups.

- Participants noted a dearth of clinical practice guidelines, the need for pregnancy-specific training during residency and beyond.
- Participants recommended all healthcare staff be included in training opportunities

3) Desired educational outcomes of training including increasing knowledge, enhancing attitudes, and developing practical skills for caring for and communicating with pregnant women with IDD.

CONCLUSIONS

- Our findings indicate that inadequate knowledge, lack of confidence, and lack of guidelines may prevent clinicians from providing comprehensive obstetric care to women with IDD.
- Additionally, clinicians may harbor negative attitudes or stereotypes regarding sexual and reproductive health for women with IDD.
- These findings highlight the need for healthcare professionals to receive formal training in caring for women with IDD, support the need for development of clinical practice guidelines, and suggest a need for tools to support clinicians when caring for women with IDD.

THEME 1: NEED FOR TRAINING

"Since there's no official training that happens in residency, and there's probably a lecture on developmental delays in medical school, but not specifically for pregnancy. I think every doctor has the same ability to take care of these patients, and it's poor."

"We're not trained. I'm not trained. I don't feel confident."

"...I think a lot of people feel very ill-equipped to do all the right things even though we know how to deal with other populations."

THEME 2: RECOMMENDATIONS

"You can make it part of residency training. You could make CREOG questions..."

"Maybe sample sentences or phrases that you could use for a patient to simplify things. Options for anesthesia and ways to simply address that. Direction for social services support, expectations of social services support."

"I think what would be helpful would be some sort of practice bulletin... materials that we could give to patients, materials that we could give to clinicians that were simple..."

THEME 3: DESIRED EDUCATIONAL OUTCOMES

Increasing Knowledge

"I think one of the most difficult issues I find is a legal issue sometimes with who is the decision maker, who is going to take care of the baby afterwards, because the patient might really want to take care of that baby. But it's a question if she's able to or not..."

Developing Practical Skills

"I have to be much more explicit and basic... counseling takes much more times, and a visit may be twice as long or three times as long as the other patient who is of normal intelligence."

Enhancing Attitudes

"I think that's been really well-established that doctors have a different idea about what a life worth living is compared to the general population. And we see this in obstetrics ... I think doctors have this idea that people with disabilities shouldn't be living. I'll just be honest."

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